an IPOPI event

IPOPI ASIAN PID PATIENTS AND DOCTORS MEETING

1–2 MARCH 2026

BANGKOK, **THAILAND**



IPOPI

IN COLLABORATION WITH:

SEAPID

SUPPORTED BY:

GRIFOLS CSL Lacar THE Lebien Family IPOPI Participation Fund

IPOPI was delighted to welcome participants to the Asian PID Patients and Doctors' Meeting in Bangkok - an inspiring event that brought together close to 60 patient representatives and healthcare professionals from 14 countries throughout the region.

Over two engaging days, attendees participated in a dynamic programme featuring expert presentations, panel discussions, and interactive workshops designed to foster collaboration, knowledge exchange, and empowerment among the Asian PID community.

Access the meeting agenda and participant list in annex I and II. Please find the presentations on our website and the pictures **here.**

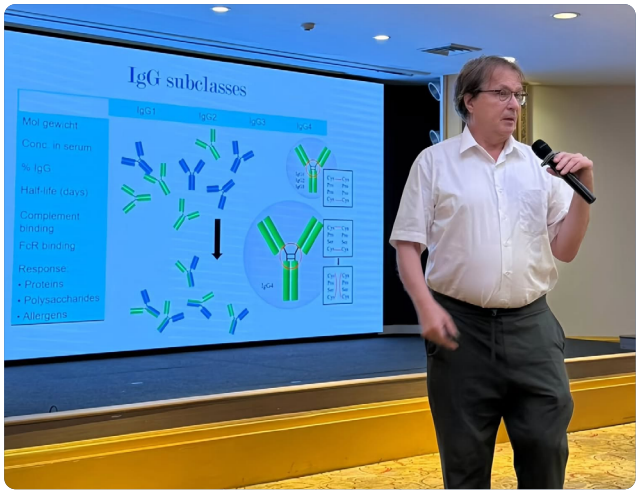


Day 1
Sunday, 1 March 2026

Session 1: Welcome

The meeting opened with **welcome remarks** from IPOPI President Martine Pergent, ThaiPOPI President Ronnaphee Nushsiri, and representatives from Grifols and LaCar. The meeting also benefited from the support of the LeBien Fund. An interactive icebreaker session followed during which participants were invited to share insights, explore similarities and differences, and express their expectations for the meeting.

Next, introductory presentations looked at how AI today can support the treatment of PIDs complemented by insights from the region. These opening discussions **set the scene** for the day's subsequent sessions.









Session 2: The Diagnosis Pathway

This session explored key developments and challenges in improving the diagnosis and long-term management of primary immunodeficiencies (PIDs), with a particular focus on newborn screening, genetic testing, transition to adult care, and distinguishing primary from secondary immunodeficiencies. Speakers shared experiences and initiatives from across Asia and beyond, highlighting the importance of early diagnosis, multidisciplinary collaboration, and patient-centred care.

Key takeaways:

- Early newborn screening can significantly improve survival and long-term outcomes for patients with SCID and XLA by enabling earlier treatment.
- Japan and Malaysia shared experiences in expanding newborn screening programmes and highlighted remaining regional inequalities in access and funding.
- Genetic testing and counselling are becoming increasingly important for accurate diagnosis, better prognosis, personalised treatment, and family support.
- Distinguishing primary from secondary immunodeficiencies can be challenging as some secondary immunodeficiencies sometimes hide a previously undetected underlying primary immunodeficiency. Multidisciplinary collaboration namely between hematologists and immunologists is required.
- Artificial intelligence and new diagnostic tools may help identify patients with underlying PIDs earlier, and ensure them treated for the underlying condition rather than just the symptoms.
- Regional collaboration, education, and standardised screening approaches are essential to improve diagnosis and access to care across the region.



Session 3: Plasma Collection and Immunoglobulin Therapies

Exploring the challenges and opportunities surrounding plasma collection, immunoglobulin (IG) therapies, and access to treatment across Asia. Discussions focused on the growing demand for IG therapies, regional inequalities in access, and the importance of advocacy, collaboration, and sustainable plasma collection systems. Following points where highlighted:

- **Access to immunoglobulin therapies remains highly unequal across Asia,** with major differences in diagnosis rates, availability and coverage policies between countries.
- **Plasma** is a critical and limited resource and increasing plasma collection is essential to ensure **sustainable access** to life-saving therapies for PID patients.
- SCIG access remains limited in many parts of Southeast Asia despite its benefits for patient independence and quality of life as well as those with challenging vein access.
- Underdiagnosis of PIDs and low immunoglobulin consumption in many countries continue to mask the true regional need for treatment.
- It is important to **educate stakeholders, regulators and policymakers** about safe use of IG therapies, including awareness of side effects, infusion management, and individualised treatment approaches.
- **Regional and national collaborations,** including public-private partnerships, are helping strengthen plasma collection systems and local fractionation capacity.
- Indonesia shared its successful advocacy efforts to include IVIG in the national formulary, highlighting the importance of patient stories, media engagement, and collaboration with healthcare professionals and policymakers.
- Continued **advocacy, medical education, and stronger policy engagement** are needed to improve diagnosis, national coverage plans, and equitable access to immunoglobulin therapies across the region.



Session 4: Curative Treatments

This session explored the latest advances in curative treatment options for primary immunodeficiencies (PIDs), with a particular focus on hematopoietic stem cell transplantation (HSCT), regional collaboration, and emerging gene therapies. Speakers highlighted how advances in transplantation techniques, multidisciplinary care, and international partnerships are enabling more patients across Asia to access potentially curative treatments. The session also showcased real-world experiences demonstrating that successful transplant programmes can be developed even in resource-limited settings through collaboration, knowledge sharing, and careful planning. Looking ahead, gene therapy is emerging as a promising new treatment option that may further expand access to curative care.

- **HSCT** is an established and increasingly accessible curative treatment for many PIDs, with outcomes continuing to improve through earlier diagnosis, advances in transplantation techniques, and comprehensive multidisciplinary care.
- Early diagnosis and **timely transplantation are critical for achieving the best outcomes.** Patients transplanted before severe infections or organ damage develop have significantly higher survival rates, underlining the importance of newborn screening and rapid referral to specialist centres.
- Successful transplantation depends on careful, **individualised decision-making,** including selection of the most appropriate donor, conditioning regimen, stem cell source, and supportive care based on each patient's clinical condition and available resources.
- Real-world case studies from Vietnam demonstrated **how international collaboration, technical support, and knowledge exchange enabled the development of the country's first successful PID transplant programme,** transforming local capacity and improving long-term access to curative care.
- **Regional partnerships** between clinicians, transplant centres, laboratories, industry, and international experts play a vital role in overcoming technical, logistical, and financial barriers, allowing patients to receive treatment closer to home.
- The session emphasised that **treatment decisions should prioritise providing the safest and most appropriate option available within each country's healthcare setting,** rather than striving for an ideal approach that may not be feasible.
- Gene therapy is rapidly evolving as a promising curative approach for many PIDs, particularly for patients without suitable stem cell donors. Ongoing clinical trials are demonstrating encouraging early results, including immune reconstitution in patients with RAG1-SCID, while continued research aims to expand access to additional genetic disorders. Consideration should be given to how gene therapy development could be further encouraged in Asia.

Session 5: Supporting the Journey to Adult Care

This session explored the importance of supporting people with primary immunodeficiencies (PIDs) beyond medical treatment, with a focus on **mental health, family support, patient empowerment,** and the **transition from paediatric to adult care.** Discussions highlighted the need for holistic, multidisciplinary care that enables patients and families to build resilience, develop self-management skills, and navigate adulthood with confidence.

- **Mental health is an essential part of comprehensive PID care,** as patients and caregivers often experience anxiety, emotional stress, even depression, and reduced quality of life.
- Education and empowerment help **reduce stigma, promote self-advocacy, and prepare children and young people for greater independence** of the transition to adult care.
- The transition from paediatric to adult care should begin early and include medical, psychosocial, and educational support.
- **Practical coping strategies, peer support, and caregivers' wellbeing** are important for building resilience and improving long-term outcomes for both patients and families.
- A **family-centred, multidisciplinary approach is key to addressing the emotional, social, and practical challenges** associated with living with a chronic condition.

Key takeaway: Participants highlighted the need for structured transition programmes and improved access to adult immunology services to ensure continuity of care across Asia.





Session 6: Crafting Tomorrow - A Strategic Action Workshop

The last session of this meeting featured an interactive workshop for all the participants, focusing on translating the learning and exchanges emanating from the meeting into **concrete actions for the NMOs.** It combined examples of impact from across the region with a collaborative workshop designed to help participants define priorities and identify practical next steps.

The session opened with a **"speed dating" exchange** showcasing the impact that different projects have had for the region. These examples provided practical inspiration from four different Asian NMOs.

The workshop then encouraged participants to reflect on what they had learned during the meeting - including new knowledge about the PID field, regional opportunities and concrete examples of NMO activities - and consider how these insights could be turned into action. Participants were asked to imagine where they wanted their NMO and PID community to be **in two years,** what they hoped to have achieved, and what should be different for PID patients in their country.

Each country identified three potential goals and then selected **one key goal for the near future,** reinforcing the importance of prioritisation rather than attempting to address everything simultaneously.

A strong emphasis was placed on **regional collaboration.** Participants worked with neighbouring countries to brainstorm how their respective key goals could become reality, considering opportunities to share resources and expertise, learn from one another's experience and address common challenges together. Importantly, the exercise concluded by asking participants to identify **one first step they could take immediately,** moving the discussion from ambition to implementation.

The session closed by highlighting the extensive **support IPOPI offers to its NMOs**. This includes educational materials and leaflets, webinars and mini-documentaries, the NMO toolkit covering areas such as strategy, governance, awareness and fundraising, IPOPI statements, NMO development and participation grants, and community channels such as Webchat and e-news communications and the NMO global WhatApp.

Key takeaway: The session provided a practical bridge between **learning and implementation,** encouraging NMOs to leave the meeting with a clear priority, stronger opportunities for regional cooperation, and an achievable first action toward improving the situation of PID patients in their countries.

Conclusion

The meeting highlighted key priorities for strengthening PID care across Asia: earlier diagnosis, expanded access to newborn screening and genetic testing, equitable and sustainable access to immunoglobulin therapies, and timely access to curative treatments. Participants also emphasised the importance of a structured transition to adult care alongside a holistic approach addressing patients' mental health, empowerment and long-term wellbeing.

Throughout the sessions, regional collaboration, education and knowledge-sharing emerged as critical drivers to reduce inequalities in diagnosis and treatment and strengthen national healthcare capacity. Patient organisations are essential to this progress through advocacy, awareness, patient support and engagement with healthcare professionals and policymakers. The meeting concluded with a strong focus on turning shared learning into action, encouraging each NMO to identify clear priorities, practical next steps and opportunities for collaboration across the region.



This meeting was made possible thanks to the support of GRIFOLS, Lacar and THE Vebien Family

Annex I – Agenda

IPOPI Asian PID Patients and Doctors' Meeting

PROGRAMME

1 MARCH (MORNING)

TIMINGS	CONTENT	SPEAKERS
08:40 - 09:00	Welcome & Registration	
	Session 1 – Welcome Session *Moderator: Martine Pergent, IPOPI President*	
09:00 - 09:10	Welcoming remarks and introduction to IPOPI	Martine Pergent, IPOPI President
09:10 - 09:15	Welcome to Thailand	Ronnaphee Nushsiri, ThaiPOPI President
09:15 - 09:25	Welcome from sponsors	Grifols and LaCar
09:25 - 10:00	Icebreaker	Miriam Ferreira and Alicia Bartos, IPOPI NMO Programmes Team
10:00 - 10:15	Innovative approaches in PID care - use of AI	Prof Adli Ali, Malaysia
10:15 - 10:25	Challenges of PID awareness in the Himalayan region (Nepal and Bhutan)	Dr Dharmagat Bhattarai, Nepal
10:25 - 10:30	Questions & Answers	
10:30 - 11:00	**Coffee Break**	
	Session 2– TheD iagnosis Pathway *Moderators: Dimas Sugiharto, IPOPI Regional Board Member and Prof Surjit Singh, India*	
11:00 - 11:15	Newborn screening for PIDs in Japan	Prof Hirokazu Kanegane, Japan
11:15 - 11:20	Newborn screening programme in Malaysia	Bruce Lim, IPOPI Vice-President
11:20 - 11:35	Genetic testing and counselling	Dr Nizar Mahlaoui, IPOPI MAP Chair
11:35 - 11:50	Secondary Immunodeficiency and underlying PID	Prof Silvia Sánchez Ramón, IPOPI MAP Vice-Chair
11:50 - 12:00	Questions & Answers	
12:00 - 12:30	Discussion: Regional collaboration to improve diagnostic access and reimbursement	Dr Hirokazu Kanegane; Bruce Lim; Dr Nizar Mahlaoui; Prof Silvia Sánchez Ramón; Iqbal Hossain, Bangladesh; Lenny Susanti, Indonesia.
12:30 - 12:45	Group Picture	
12:45 - 14:00	**Lunch Break**	

IPOPI Asian PID Patients and Doctors' Meeting

PROGRAMME

1 MARCH (AFTERNOON)

TIMINGS	CONTENT	SPEAKERS
Session 3 – Plasma Collection and Immunoglobulin Therapies *Moderators: Johan Prevot, IPOPI Executive Director and Prof Yae-Jean, South Korea*		
14:00 - 14:15	Plasma collection and IG access in Asia	Grifols/IPOPI TBC
14:15 - 14:30	Everything you never had the chance to ask about the clinical use of Immunoglobulin replacement therapy	Prof Martin van Hagen, Netherlands
14:30 - 14:45	Development of access and reimbursement of IVIG in Indonesia	Dimas Adhi Sugiharto, IPOPI Regional Board Member
14:45 - 14:55	Questions & Answers	
14:55 - 15:45	Collaborative Workshop: Discuss actionable steps to have IG reimbursement at a national level	Facilitator: Martine Pergent, IPOPI President
15:45 - 16:15	**Coffee Break**	
Session 4–C urative Treatments *Moderators: Dr Nizar Mahlaoui, IPOPI MAP Chair and Dr Narissara Suratannon, Thailand*		
16:15 - 16:30	Transplantation advances in the region	Dr Jia Hou, China
16:30 - 16:45	Successful collaborations in the region on transplantation - the case of Vietnam and Hong Kong	Prof Pamela Lee, Hong Kong
16:45 - 17:10	The latest developments in gene therapy	Prof Frank Staal, Netherlands
17:10 - 17:25	Questions & Answers	
17:25 - 17:30	Closure of the day	Bruce Lim, IPOPI Vice-President

IPOPI Asian PID Patients and Doctors' Meeting

PROGRAMME

2 MARCH

TIMINGS	CONTENT	SPEAKERS
Session 5 – Supporting the Journey to Adult Care *Moderator: Bruce Lim, IPOPI Vice-President*		
09:00 - 09:10	Opening and energiser	Bruce Lim, IPOPI Vice-President
09:10 - 09:25	More than physical - caring for mental health in PIDs	Dr Pon Trairatvorakul, Thailand
09:25 - 09:35	Questions & Answers	
09:35 - 10:15	Discussion: What do we do with the adult patients?	Facilitator: Prof Adli Ali, Malaysia
10:15 - 10:30	Questions & Answers	
10:30 - 11:00	**Coffee Break**	
Session 6– Crafting Tomorrow: AS trategic Action Workshop *Moderators: Miriam Ferreira and Alicia Bartos, IPOPI NMO Programmes Team*		
11:00 - 11:05	Introduction to the Speed Dating: Showcasing impacts from the region	Alicia Bartos, IPOPI NMO Programmes Officer
11:05 - 11:45	Speed Dating: Showcasing impacts from the region	Presenters: Jessie Qu, PID Care China; Lenny Susanti, IPIPS Indonesia; Miho Yanai, PID Tsubasa-no-Kai, Japan; Siti Aminah, MyPOPI, Malaysia.
11:45 - 11:50	Introduction for the Workshop: Crafting Tomorrow Together	Miriam Ferreira, IPOPI NMO Programmes Manager
11:50 - 12:20	Workshop: Crafting Tomorrow Together	
12:20 - 12:25	Wrap up	Miriam Ferreia and Alicia Bartos, IPOPI NMO Programmes Team
12:25 - 12:40	Closure of the day	Martine Pergent, IPOPI President and Bruce Lim, IPOPI Vice-President
12:40	**Lunch Break**	

Annex II – Participants

Iqbal Hossain and Prof Mohammad Imnul Islam. (Bangladesh)

Jessie Qu and Dr Jia Hou. (China)

Prof Pamela Lee. (Hong Kong)

Mayakant Shukla, Prof Surjit Singh. (India)

Lenny Susanti and Dr Alvina Widhani. (Indonesia)

Miho Yanai, Takuro Yanai and Prof Hirokazu Kanegane. (Japan)

Sysomphone douanglasy and Alounna malaydeth. (Laos)

Siti Aminah Amir, Karen Koh, Dr Adli Bin Ali, Mr Fadzhairi and Dr Thin Thin. (Malaysia)

Sandip Paudel and Dr Dharmagat Bhattarai. (Nepal)

Prof Frank Staal. (Netherlands)

Theodore Ray Sosoban and Dr Jonie Tillah. (Philippines)

Dr Bianca Chan and Arunachalam Thannirmalai. (Singapore)

Prof Yae-Jean Kim. (South Korea)

Dr Yin-Hsiu Chien. (Taiwan)

Ronnaphee Nushsiri, Narumon Jitchanwichai, Ekawat Suwantaroj, Doungpond Nushrisi, Thunsuda Sailabaht, Patikarn Chinsirichokchai, Dr Dew Kornavalee, Dr Narissara Suratannon, Dr Pon Trairatvorakul, Anthony Ryan, Kanyakorn Nawanin Ryan and Thephatsadin Nongkanang. (Thailand)

IPOPI

Martine Pergent, Johan Prevot, Bruce Lim, Dimas Adhi Sugiharto, Dr Nizar Mahlaoui, Prof Martin Van Hagen, Prof Silvia Sánchez Ramón, Miriam Ferreira and Alicia Bartos.

CSL

Dr Yi Xian.

GRIFOLS

Dr Jessie Low.

Lacar

Dr Nora Benghalem and Dr Florian Bohet.

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